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ABSTRACT

A program for severely handicapped preschool children in Camden, New Jersey, provides a supportive environment to the families in response to urban stress factors. Staff members, sensitized to working with a multicultural population, act as parent advocates. Family contacts begin with explaining the child's diagnosis, establishing a supportive relationship, setting objectives, coordinating other services as needed, and involving family members as they wish in the program. The effects of poverty and urban sociocultural factors on the young child's physical health, home environment, and family structure are reviewed. (CL)

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PRIORITIZING WITH PARENTS OF SEVERELY HANDICAPPED PRESCHOOL CHILDREN

Council For Exceptional Children:
Conference on the Exceptional Black Child
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Program Overview

Camden, New Jersey is an urban center with a school population of approximately 20,000. This population is composed of 65 percent Black, 28 percent Hispanic and 7 percent Caucasian. [1]A large proportion of the population exists on below poverty level income or receives public assistance. The city itself has many financial problems and much of the industry that flourished in this port city during World War II has diminished or departed. The thriving businesses on the main street are now boarded up, surrounded by poor or inadequate housing.

The Program for Severely Handicapped Preschool Children was funded by the Bureau of Education for the Handicapped (BEH) in 1977 as a three year demonstration project. It is presently supported by Title VI-B funds through the New Jersey Department of Education.

[1]Figures taken from Camden City Public School's System Race, National Origin Desegregation Plan, FY1980, James Brown

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As an urban project formerly within the Handicapped Children Early Education Program (HCEEP) network, it incorporates all of the components of HCEEP. This includes services to children, services to families, interagency coordination services, staff training, and dissemination activities. However, its unique and most distinctive features reflect the needs and characteristics of the area it serves. While the project supplies a quality program on an instructional level, it also provides a supportive environment in response to the multi-problem inner city population. It is a program that works because it deals with the realities of the city, and those stress factors that interfere with parent and child progress.

Successful preschool and infant programs are those in which parents and providers work together. In an urban setting, the problems encountered in implementing a program for the severely handicapped with parental involvement are many. It is necessary to acknowledge the ecological situation of the family prior to initiating an individualized educational program for the child or parent training. The family treatment specialist must establish realistic priority areas with parents and provide assistance through the coordination of community agencies[2] to help parents and project staff plan together for the family. The treatment of the child in an isolated classroom sense does not answer the global needs of the family unit.

[2]See Appendix for Interagency Coordination Chart.

Project staff must recognize the level of parental readiness, the parents' ability to attain basic needs to support life, the specific information and training needed to deal with a particular handicap, and the necessity of building selfesteem in the parent to encourage participation. Any remediation for the child must be approached with a clear understanding of total family needs so that all participants have reasonable expectations. When the parent helps to define priorities in an atmosphere of trust, and providers recognize the environmental pressures, the cooperative relationship is enhanced. Techniques and methodologies of exemplary programs mean very little to the family concerned with adequate housing, food, clothing, or medical care. Before applying remediation to a handicap it is necessary to understand human behavior in a particular setting. (Apter 1977). Then, with sensitivity and patience, providers may begin to think in terms of the objectives in the child's IEP.

As the family treatment specialist works with the family, the child is placed in the transdisciplinary program for severely handicapped. The staff, consultants and medical community observe and evaluate the child so that an appropriate program can be designed. Four or five sessions per week are provided on site, on a half-day basis, with a home-based program scheduled if necessary. The program philosophy is cognitive developmental with behavioral techniques used if needed. The children in the group represent a variety of severe handicaps in the motor, communication, intellectual or emotional areas. Frequently, children also have serious health problems or seizure activity.

Whenever possible, one-to-one intervention is provided through teaching staff, aides, CETA workers, high school students and parent volunteers. The severely handicapped infants especially require individual attention, while the older children (three to five) have many group socialization activities. For all youngsters, data collection is done on specified objectives to provide ongoing monitoring of progress. The staff also assesses children twice a year using the Early Learning Accomplishment Profile (E-LAP) or the Learning Accomplishment Profile (LAP). Many daily activities are taken from the Nisonger Infant Stimulation Curriculum or provided through consultants in physical therapy, speech and feeding or parents. As parent involvement increases, participation in the development of the IEP and the training program will reflect the parents contribution. The total program for the family will assume a more holistic nature as parent integration is achieved.

It is important that a program for minorities reflect the multicultural population it represents. Staff members can be sensitized to other cultures in many ways. Ideally teacher training programs should provide preservice training in this important area. However, ongoing inservice programs using parents and consultants will also be helpful. Staff/persons must recognize their own beliefs and biases and openly experience and observe the culture of other ethnic groups.

Listening is an essential ingredient to understanding other cultures; educators frequently are talkers and directors. It is the responsibility of program staff to demonstrate a respect for contributions of parents to help them to feel free to express their views. Adequate representation by minorities on the staff and parents to participate. The recognition of culturally transmitted behaviors and learning styles by program staff, in addition to ethnic childrearing practices will add depth to interaction with families (Bowen and Salzman, 1979). Frequently these practices may not be consistent with the program model and an understanding must be reached between parents and providers (Chan and Rueda, 1979). Value conflicts need to be identified and resolved before caseplanning is done. Time together, the sharing of ethnic views and educational practices will help to break down conflicts which emerge as family traditions and educational practices are revealed. The lack of cultural sensitivity can create serious road blocks to service provision and cause frustration for parents and staff (Baca, 1980). In the cities where educators and students have not developed the multi-cultural view point, the problem of non-participation and staff turnover can be acute.

In the city of Camden, a newly developed desegregation plan supports the concept of multicultural teaching methods being recommended by many state departments of education. A survey conducted in 1976 by the Multicultural Educational Commission indicates that sixty-eight percent of the states passed legislation and developed policy related to multicultural education (Baker, 1979).

On the Federal level, the Ethnic Heritage Program legislation passed in 1972, encourages the study of ethnic and racial minority cultures by school children in the United States. Title IV of the 1964 Civil Rights Bill provides technical and financial assistance to desegregation efforts in local school districts. Universities and colleges give credence to multicultural education practices and are beginning to include course work in their teachers' training programs. While all of these efforts are commendable, it is important to remember that those who provide services must avoid stereotyping or negative expectations (Henderson, 1980).

To build self esteem in a parent the educator must be a parent-advocate. Parents need to know that their opinions, help and participation are important to the child and program. In order to recognize this importance, parents must realize that their voices count in all decisions regarding the child's program. Staff people who work with minority parents have a responsibility to inform them about Public Law 94-142, Education for all Handicapped Children Act of 1975. Due process procedures should also be provided to parents, both verbally and in written form. It has been clearly demonstrated in a recent study completed by the New Jersey Department of Education that minorities are over-represented in special education programs on a statewide basis.[3]

[3]The Status of Minority Group Representation in Special Education Programs in the State of New Jersey: A Summary Report. New Jersey Department of Education. November 1980

Although there are four times as many Caucasian children in New Jersey classrooms, forty-three percent of all Educable Mentally Retarded children are Black. This equals approximately the same number of Caucasian youngsters in EMR classes. These figures demonstrate the urgency of providing information to minority families on testing procedures, classifications and types of programs within their area. Parents should also be encouraged to:

- work with other parents
- work with professionals
- use their right to speak
- stop pleading, education is a right
- learn how to take part in planning conferences
- not compromise but insist on full evaluation and clear goals
- be an active citizen (U.S. Dept., HEW, 1976b,p^{2}.)

Defining Needs and Establishing Communication with Parents

Parent involvement is a strong and active component of the preschool program in Camden. Parent contact is the first step in the referral process and is scheduled promptly by the family treatment specialist. Most often the family treatment specialist makes the first visit in the home unless parents prefer not to. In this way, parents and other significant family members are free to speak openly in the comfort of their home concerning the handicapped child. Frequently, ambivalent feelings and anxieties emerge especially where an infant is involved. Often there is not a clear understanding of the child's diagnosis or prognosis.

From this initial dialogue, the family treatment specialist can determine a sense of the direction to be taken with this family in distinguishing between the feelings directly related to the handicapped child and those related to a stressful life situation. Many of the families are within the economically deprived category, and concern for material needs takes precedence over the preschool program placement.

The family treatment specialist begins with trying to understand the family's perception of their exceptional child. The family treatment specialist helps the family to explore all aspects of the situation and the possibilities for solutions. She encourages family members to examine their roles as parents or caretakers and provides them with information on the handicapped child's development. A close, supportive relationship with parents is maintained, according to the intensity of parents needs. When serious multiple problems are apparent within the family structure, and family indicates a need for intervention, regular follow-up visits with family treatment specialist are scheduled. Objectives are determined with family input, and strategies are mapped out in order to achieve them. When the family feels that objectives have been met, the services are terminated. However, parents maintain contact through group meetings, individual counseling sessions, classroom visitation and parent training. The parent is always free to request any additional services when problems arise.

Family members have indicated verbally and in writing that they feel welcome at the project. Communication has been open; parents frequently stop by and sometimes remain for the session. Many parents have become strong advocates for preschool education providing information to the community and legislators concerning the needs of the handicapped. Some have emerged as active participants and able group leaders during parent meetings. Other parents have been able to provide the empathy and support necessary to assist new parents as they enter the program. Often parent progress in social, emotional and skill areas exceeds the child's progress. Parent priorities and levels of readiness are carefully noted by the family treatment specialist, as she assists the family through feelings of grief, anger, helplessness and depression. Increasing parent self-esteem is an important factor in parental preparation; understanding the exceptional child, knowing parents rights, involvement in funding issues are activities that help build self-respect. Staff members must demonstrate parent advocacy and sensitivity to family conditions to encourage parents to participate.

The family treatment specialist gives consideration to the following factors when working on parenting skills with families:

- parent education for coping and preventing emotional stress
- specific child care practices

- attitudinal change and adaptation
- sharing experiences in study groups
- reaffirming importance of child-rearing and parental roles.
- understanding principles of child growth and development
- understanding children's behavior
- discovering ways of handling specific behaviors
- parent contribution to prevention, treatment and care of child with handicap

Although many parents do not achieve success in all areas listed, there have been numerous incidents of real growth in parenting skills.

Problems of the Urban Setting

The development of the fetus can be influenced by socio-cultural factors. The mother is not impervious to her social surroundings and neither is the fetus. This is true even though the tiny fetus seems to be protected and remote from the society into which it is born. Robinson and Robinson contend that "mothers from more favorable backgrounds tend to make better use of reliable sources of obstetrical information and care, to have better diets and a better general state of health, to have their babies at more favorable ages, and so on" (1976, p.115). These factors bear relationships to various incidences of complication during pregnancy, prematurity, congenital malformations and brain damage. May of these factors are interrelated on a broad continuum.

The degree of severity with which the environment influences the integrity of the developing individual varies from severe congenital anomolies to the advent of a healthy child. Robinson and Robinson (1976) explain that "some children weather successfully much the same conditions which seem to produce retardation in others". The authors add that "family conditions which may lead to acceleration during one period of development may lead to deceleration in other". (p.147)

The presence of mental retardation and most health and social problems exist in poorer urban areas. The incidence is much higher in these environments, which are characterized by overcrowding, increased maternal and infant mortality rates, poor infant care, high birth rate, social disorganization, delinquency, and frequent illegitimacy.

Many children in depressed areas seem severely affected in their intellectual attainments by a complexity of conditions in their immediate environment. A report from the Office of Education points out that "crime", alcoholism, drug addiction, poverty, illiteracy, disease, unemployment and broken families are found in city slums in massively greater degree than in society as a whole" (Passow, 1962,p.1.) Passow describes the depressed area population as a stratified group of predominantly unskilled or semi-skilled workers, who have moved from a rural area to an inner city setting, largely from minority groups.

Robinson and Robinson (1976) attempt to give rationale concerning conditions of poverty which predisposes toward mental retardation. The causes of mental retardation are very complex and interwoven and are therefore inclusive of many factors. The major relevant dimensions of poverty are herewith divided into five areas.

(1) Physical Health - children born to poorer families are exposed from the moment of conception to a greater risk of damage to their physical integrity - inadequate nutrition. Bacterial and viral infections, chronic dysfunction in the mother, exposure to toxic substances, and frequently, closely spaced and complicated pregnancies.

In Poverty Stricken Families

-- prematurity is more common
-- postnatal mortality is much higher
-- psychosocial retardation is due greatly to damage to the central nervous system
-- documentation of physical hazards is abundant
-- perinatal deaths (congenital pneumonia or wide spread infections) are twice as common
-- exposed to greater health risks and health care

(2) The Home Environment - Substandard living condition - (overcrowding, lack of hot water, poor temperature controls, infestations of rodents, flaking lead-based paint, unprotected stairs, open heaters, and lack of safe outdoor play space), are contributing factors to poor physical status. Other physical effects on health and intelligence are: lack of educational toys and material; conducive environment for study and involvement; one's own space-bed; room to be messy, noisy.

The living conditions of the poor have other consequences for childrearing. As a detriment to child development these conditions operate:

-- The passive and conforming child is valued;
-- Home becomes a place from which to escape;
-- Poor children have little exposure to the kinds of materials they will use in school;
-- Home is likely to be disorganized and chaotic;

(3) Practical Difficulties - Life presents a seemingly endless series of nagging problems to most families with limited resources.

(4) Family structure - Fewer adults and more children characterize the poor family. There is a negative relationship between family size and intelligence; (Clausen and Clausen, 1973) - Although most poor families have male heads, in 1970, 31 percent of Black families having children under the age of eighteen were headed by a woman, whereas eight percent of such white families had females heads. "Black and White differences are here taken as indices of socioeconomic differences." Mothers in poor families have an inordinate share of responsibility for the children, with only minimal kinds of support;

-- fathers are apt to spend little of their leisure time at home and assume a minor role with their children
-- fathers tend to drift out of touch with their own families (because of working, time, etc.)
-- without a father, stresses are likely to mount unbearably on the mother

(5) Childrearing Patterns - Poverty families experience numerous difficulties that influence the potential success of children and lead into retarded situations. Parents are hard-pressed by problems of daily living which bring about loneliness, discouragement and depression. The course of their children's development is not stimulated due to the parents feelings of helplessness.

Some aspects of child-rearing practices as seen by Robinson et. al. include:

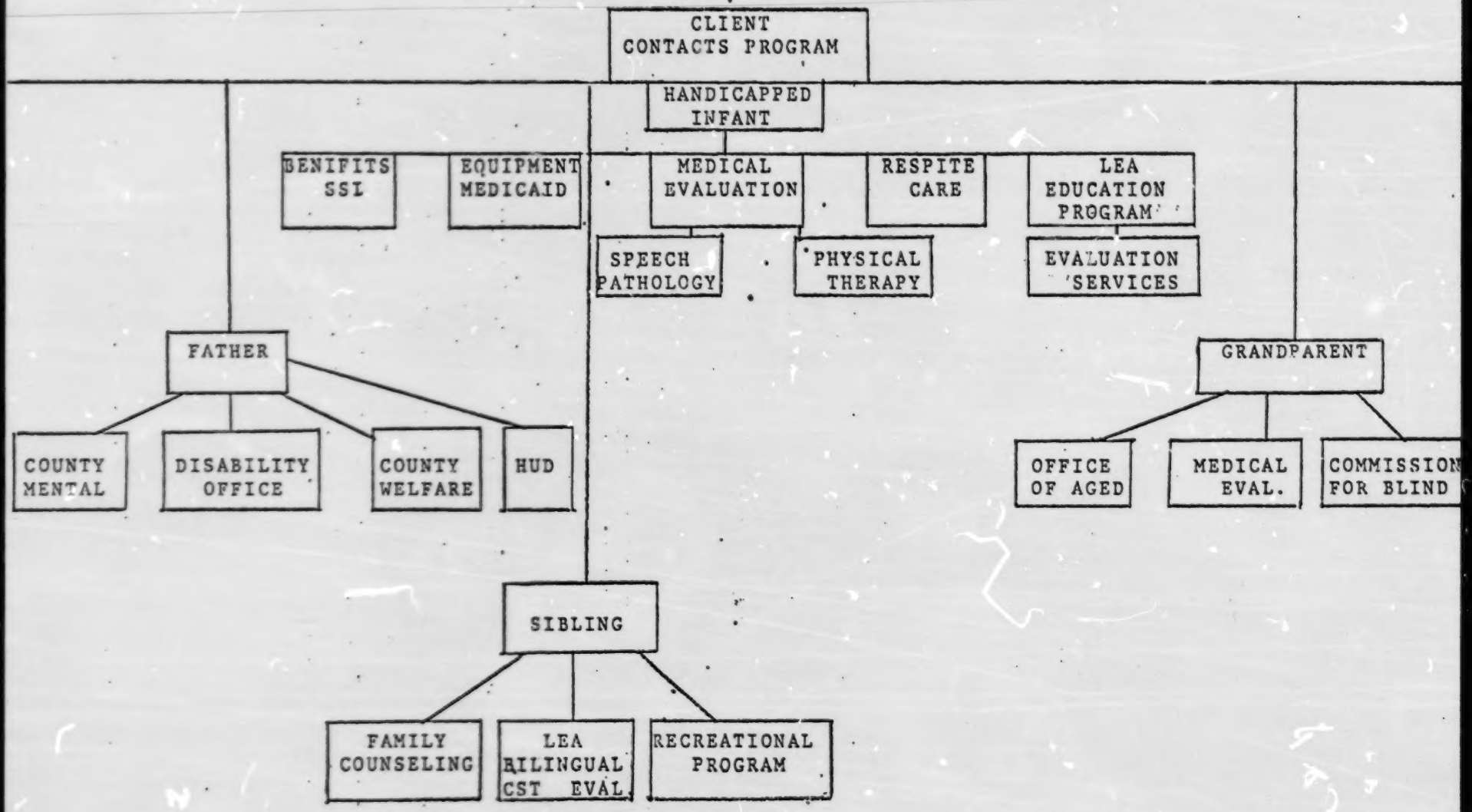
-- a reliance on authoritarian methods
-- a status-oriented approach that's inflexible and offers no recourse.
-- a reliance on punishment (physical)
-- a rather ineffective teaching technique
-- a method of external rather than internal controls
-- a delay in teaching independent tasks until child is capable of rapid performance and accurate projections (eating with spoon, drinking from cup, etc. without making a mess)

The literature reveals the fact that retarded children from lower socioeconomic groups have untapped potentials for success. This is so because the child has a tendency to retreat from situations that might suggest failure.

The issues, problems, and concerns offered in this presentation on poverty are very peripheral. The effort has been to show the differences from a stand point that projects heavily on the extreme end of the continuum. The poor have learned many ways to cope with problems of living. Their survival skills are outstanding and differ greatly from the ways middle-class families cope with similar conditions. However, as Robinson, et. al. contend, there can be no doubt that a realistic portrayal of poverty must be a bleak one. "Efforts to improve the life situations of the poor may be the single most important step toward preventing mental handicap". (Robinson, 1976.),p.178

CHART A

COMPREHENSIVE SERVICE COORDINATION FOR FAMILY OF HANDICAPPED INFANT



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